
The Appleton International Conference: developing guidelines for decisions to forgo life-prolonging medical treatment

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Introduction

The Appleton Conference Project began in 1987 with an international working conference for practising clinicians regarding decisions to withhold or withdraw life-sustaining treatment. Thirty-four invited participants from nine countries met over a period of four days. Each presented a case from his or her own practice in which a decision whether or not to initiate or continue a life-prolonging treatment or procedure had caused particular ethical anguish. The cases were discussed openly and candidly both in small groups and in plenary sessions; participants probed for underlying agreements, sometimes across some very different perspectives, on which they could make some basic distinctions and work towards a common basis of understanding of what is at stake in these decisions and what procedures can be most helpful in protecting what is at stake.

In the spring of 1988 a second working conference was convened. Thirty-three delegates from ten countries met to produce a model set of guidelines for discussion in medical and medical ethics communities internationally (1) that would address both decisions to forgo medical treatment, including life-prolonging treatment, precipitated by autonomous requests by patients or their surrogates, and decisions to forgo medical treatment as a result of pressures due to scarcity.

That set of guidelines was published as *The Appleton Consensus: suggested international guidelines for decisions to forgo medical treatment in the Journal of the Danish Medical Association* (1989). It was reprinted in the *Journal of Medical Ethics* (1989) and subsequently in four additional health care journals. It has now been published in five languages.

In the winter and spring of 1990 an annotated study edition of the guidelines was produced and distributed to 152 discussion groups that met in 15 countries for systematic study and comment. Those discussion groups included hospital ethics committees, hospice teams, two groups of health care economists, several groups of health care professionals (nurses, social workers, hospital chaplains, administrators, and doctors), and there was a strong representation of groups of interested people from the 'grass roots' of several societies. A total of 1450 people were involved

in the 152 discussion groups. The 94 groups from the US met in 23 different states, and the 58 foreign groups met in 14 countries (Denmark, Scotland, Israel, Sweden, Australia, Malaysia, Guinea, the Netherlands, England, Norway, Canada, India, Colombia and New Zealand). The groups spent a total of 731 hours discussing the study edition, with average length of discussion per group equalling 4.9 hours. The average size of the discussion groups was nine members. Thirty per cent of the participants were doctors; the other seventy per cent were from a variety of professions and vocations.

Each discussion group sent a report documenting its reaction to, and its suggestions for, the guidelines. In addition 749 participants returned individual participant-evaluation forms. These responses were tabulated and summarised for the delegates to a **third working conference: The Appleton International Conference: developing guidelines for decisions to forgo life-prolonging medical treatment** which met once again in Appleton in May of 1991 to respond to the suggestions, comments and challenges from the 152 discussion groups and to revise and refine the guidelines in light of those suggestions and comments.

The 24 delegates to this third conference, 20 of whom had participated in the writing of the original guidelines in 1988, were from nine different countries. They met for three and a half days in both plenary and working-group sessions, discussing the comments from the study groups, responding to the criticisms and suggestions and revising the original to produce this present document.

Notes

- (1) The original version of the guidelines was published with the following note:

Despite the wide variety of medical cultures represented, the delegates want to acknowledge that the perspectives included in this conference represented only a small fraction of the world population and did not include perspectives from Eastern Europe, the Orient, the third world and several other 'western' nations, both European and American. It is our hope that discussions provoked by the publication of these guidelines will lead to contributions from many of those perspectives.

During the study-group meeting-phase of the Appleton Project efforts were made to facilitate such contributions. Study groups were convened in Canada, Colombia, Guinea, West Africa, India and Malaysia, and new delegates were invited from India (B N Colabawalla) and Malaysia (dato' Gurmukh Singh) to participate in the third working conference. Due to emergency surgery, dato' Singh was unable to attend the conference. However, both his written report of the Malaysian study groups and Dr Colabawalla's personal contributions were influential in our deliberations. The responses from the study-groups from the previously unrepresented countries, both from groups of practising clinicians and from groups of non-medical professionals, indicated significant divergence from the 'consensus' of the Appleton group at several points: *viz*, agreeing with the published dissent in Part I, guideline 5 (euthanasia) and in Part II, guideline 13 (persistent vegetative state), and expressing the feeling that 'respect for human life' should be explicitly stated as a principle in the Preamble. Even more striking than these divergences (which paralleled the points of maximum divergence in our own group), were the very considerable areas of significant agreement, including 1) the desire to underscore the degree to which the substance of the guidelines should be intended as a model on which discussions in local medical cultures could be based rather than as universalisable truths and 2) the value of continued communication both across and within medical cultures about what is at stake in these decisions. The comments and suggestions from these previously unrepresented countries were extremely helpful in our deliberations at the final conference and constructively influenced many of our revisions. It is our hope that efforts at communication and discussion regarding these important matters continues. (John M Stanley)

Preamble: Ethical background

In caring for patients, doctors and other health care professionals, as individuals and as representatives of their professions, should act with respect for human life (1) and with integrity (2) in providing medical treatment within certain norms of care and concern.

Despite widely diverse national, cultural, religious, and political traditions, four *prima facie* moral principles summarise these norms (3,4,5).

1. *Autonomy*. All persons have a *prima facie* moral obligation to respect each other's autonomy insofar as such respect is compatible with the respect for the autonomy of all affected. This principle requires respect for patients' deliberated choices made in accordance with their own values, consciences, and religious convictions. To effect such respect, it is the responsibility of health care professionals to share information honestly and fully with patients, to enable them to collaborate fully in determining the course of their care, and to maintain patient confidentiality. While respect for the autonomy of health care professionals is no less important (and no more important) than respect for the autonomy of patients, professional integrity requires that the application of the health care professional's

autonomy always include allegiance to a norm of practice which requires *service* to patients and which assumes that the *interest of his or her patients* is always the health care professional's paramount concern.

2. *Non-Maleficence* (Avoid harm). All persons have a *prima facie* moral obligation not to harm each other. The infliction or risking of harm to others, including the risks of medical practice, can only be justified by the pursuit of other moral values – principally, in the case of medical practice, benefits to patients sufficient to outweigh the harm (6).

3. *Beneficence* (Do good). All persons have a *prima facie* moral obligation to benefit others, perhaps even especially those in need. Health care providers acknowledge a particular obligation to benefit their patients and to do so with minimal harm (7).

4. *Justice*. All persons have a *prima facie* moral obligation to act justly or fairly to others. Membership in society confers benefits, rights, and opportunities; however, in the public interest, such membership necessarily limits individual autonomy and entails obligations. Interpretation of the precise nature and extent of these rights and obligations is highly dependent on both cultural and individual perspectives. Nonetheless all societies bear the obligation to advance the general welfare of their citizens through social institutions and policies.

These four principles or values do not comprise a single ethical theory. Indeed, they often conflict and require interpretation and balancing. The four principles are given different weight in different cultures, and some cultures would wish to add additional principles or values. Moreover, substantive disagreements exist within cultures about both the scope and the relative weights of the principles. And the analysis of specific circumstances in individual cases may enhance the understanding of both ethical and cross-cultural perspectives not directly derived from the four principles. Nevertheless, acknowledgement of these principles provides a valuable cross-cultural basis for medico-moral analysis, discussion, and decision-making.

Notes to the preamble

- (1) All of the principles in the preamble reflect respect for the dignity of human life. The extent and scope of this respect is expressed in the application of the four principles. In applying respect for human life to specific cases it is important to remember that the prolongation of life, without consideration of the quality of life, may not be evaluated as being in a patient's best interest, and may not in some cases be compatible with respect for the dignity of human life.
- (2) This document begins with a statement about the importance of professional integrity to remind us of the proper function of medicine in a humane society. The earliest statement of professional integrity was in the Hippocratic oath. The importance of the Hippocratic oath was that it identified a group of people who were

prepared to submit themselves to a certain norm. By doing so, they constituted themselves as practitioners of whom certain things could be expected. Once this has happened, a society has an identifiable body of practitioners in whom certain privileges can be invested in return for the service their norms dictate. The oath and the professional integrity it commends allow one to say that certain standards have been agreed to, so that departures from those standards can be regulated by the body of practitioners concerned. On the basis of that implicit undertaking, they can do things which ordinary citizens should not do (such as run the risk of causing dangerous harm to others in order to attempt to secure certain goods). Without such standards no means exist to distinguish what will be regarded as acceptable when done by certain members of society (doctors) but not if done by others. It is expected intuitively that the kinds of things doctors are allowed to do should be regulated by the considerations of benefit with minimum harm that are enshrined in the oath.

In modern society the oath is not often taken, but the presumption that the medical profession will obey certain norms, and on that account can be trusted, remains central to medical practice as a social institution and a relationship between doctor and patient. What also remains in place is the presumption that the techniques of medical practice will not be taught unless the person learning them agrees to submit to the norms regulating this body of practitioners. Only thus can society protect itself against the illegitimate, malintentioned, or cynical use of medical techniques. In our society medicine holds hopes of great benefits but also risks of great harm.

It is, therefore, vitally important that it be regulated, so that the way it is practised puts the welfare of the patient in the highest place in medical decision-making. If the medical profession holds fast to the notion of a profession and its integrity, it maintains this standard and so guards both patients and society against the unscrupulous use of biomedical technology which is not of proven benefit. That doctors owe allegiance to a norm of practice according to which they *serve* patients and that the best interests of their patients must always be their paramount concern follows from the concept of professional integrity. (Grant Gillett)

- (3) These four principles, though individually ancient, were rearticulated in the bioethics literature in the late seventies by the philosopher Thomas Beauchamp and the theologian James Childress, *Principles of biomedical ethics* (Oxford: Oxford University Press, 1978 [2nd ed, 1983]); they were applied specifically to decisions to forgo treatment by the *President's Commission on Forgoing Life-sustaining Treatment* (Washington, DC: USPO, 1983; 83-600503), and are discussed by Raanan Gillon, *Philosophical medical ethics* (Chichester: John Wiley and Sons, 1986).
 - (4) Appeal to the four principles proposed by Beauchamp and Childress has characterised most of the best work in US medical ethics between 1970 and the present and, more recently, has begun to influence European work. To a large extent these principles capture what it has meant for medical ethics to emerge as an academic discipline in its own right, out of its origins as intraprofessional, authoritative rules and reflections. Nevertheless, the authority of these principles for a document of rules and guidelines such as this one should not obscure the lively debate that now ensues over whether such principles can exhaust the moral content of medicine to the extent their advocates have claimed. This debate, in turn, occurs against the backdrop of a broad debate in moral philosophy generally over whether ethics can be reduced to a set of rules to govern individual behaviour. One suggestion holds that only by turning attention from the isolated individual to the community can medical ethics make progress. Another is that we must replace rules-language with virtue-language and return to the task of addressing questions of character and integrity, which a rules-approach tends to ignore. A third suggestion is that we must ask, not how each of us as individuals can know that our ethical position is correct, but instead how groups or teams can reach workable compromises in the face of continued deep disagreements about moral principles. Finally, it may be argued that the four moral principles discourage discussion of issues of power and work-routine, without which moral matters in health care are incompletely characterised. Clearly these suggestions overlap to a large degree, and the fact that they are being raised suggests that medical ethics remains a vibrant field of inquiry which can hope for substantial expansion and progress in future years. (Howard Brody)
 - (5) A complementary, and occasionally an alternative system to the 'principles' approach is the 'casuistry approach'. Clinicians as well as certain religions may prefer the meticulous analysis of each individual case, taking into account all its specifics and nuances, and 'working up' towards the relevant principles, rather than applying broadly defined principles to dissimilar cases. (Avraham Steinberg)
 - (6) To a medical practitioner the principle 'do no harm' (*primum non nocere*) does not mean that one should never inflict or risk any harm at all. Medical practice is unthinkable without a willingness to risk harm to patients. It means that any harm risked or inflicted would have to be justified by reasonable expectation of benefits to the patients sufficient to outweigh the harm. Medical practitioners generally see this principle as linked to the principle of beneficence. Indeed, most would say they are two sides of the same coin. See also Grant Gillett's note on integrity above.
 - (7) 'Minimal harm' in this context means as little harm as is necessary to achieve the desired benefit.
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